

NEW SERIES PRICE 5p



The Spastics Society

MAY, 1979

## German measles: Society's warning heeded—at last

by NANCY TUFT

AT last the Department of Health and Social Security has made an open admission of the seriousness of rubella (German measles) as a cause of needless handicap to unborn babies. The DHSS has now publicly acknowledged that the number of reported cases of rubella during the first three months of 1979 has shown a marked increase compared with the same period last year.

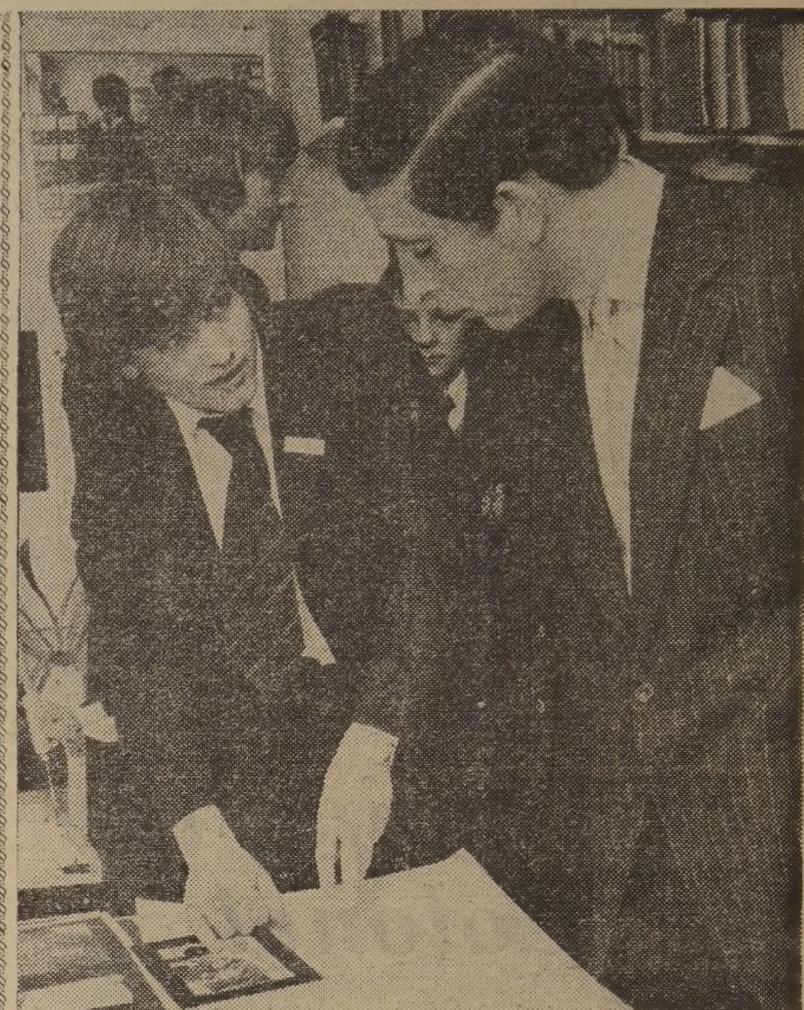
This more than vindicates the initiative taken last November by The Spastics Society which insisted on going ahead with its advertising campaign to warn women of childbearing age of the dangers they run if they are not either vaccinated or proved to be immune. This campaign was launched despite government attempts to stop it, an never since then there has been a war of words between the Society and the DHSS, which has always maintained that the Society's figures were exaggerated.

Now at last the DHSS has again announced that a campaign warning women of the dangers of rubella is to begin in the early summer. James Loring, Director of The Spastics Society, has expressed the hope that this will be a swift and widespread publicity campaign reaching into every home.

However, in view of the fact that only a few weeks ago The Spastics Society was told that a crash programme of vaccination was not feasible and that laboratory facilities for prior blood tests for testing immunity were not available, the Society would welcome assurances that these laboratory services are in fact being expanded to cope with the demand.

As The Spastics Society pointed out in its latest report on German measles (see Page 2), in order to ensure immunity in all women, it is necessary to establish which women have acquired natural immunity and which have not.

Without the necessary back-up services, no campaign can possibly succeed, and the tragedy of children born needlessly handicapped will be repeated yet again.



## Prince meets boys who help Society students

THE Prince of Wales pictured during a visit to the London headquarters of Community Service Volunteers, where he met two sixth-formers who are studying the practical problems of handicapped people as part of their 'A' level design course.

Both boys, 18-year-old Clive Waters and 18-year-old Jonathan Christie, are from Sevenoaks. Jonathan's design project has involved working with severely handicapped students from The Spastics Society's Thomas Delarue School in Tonbridge, who

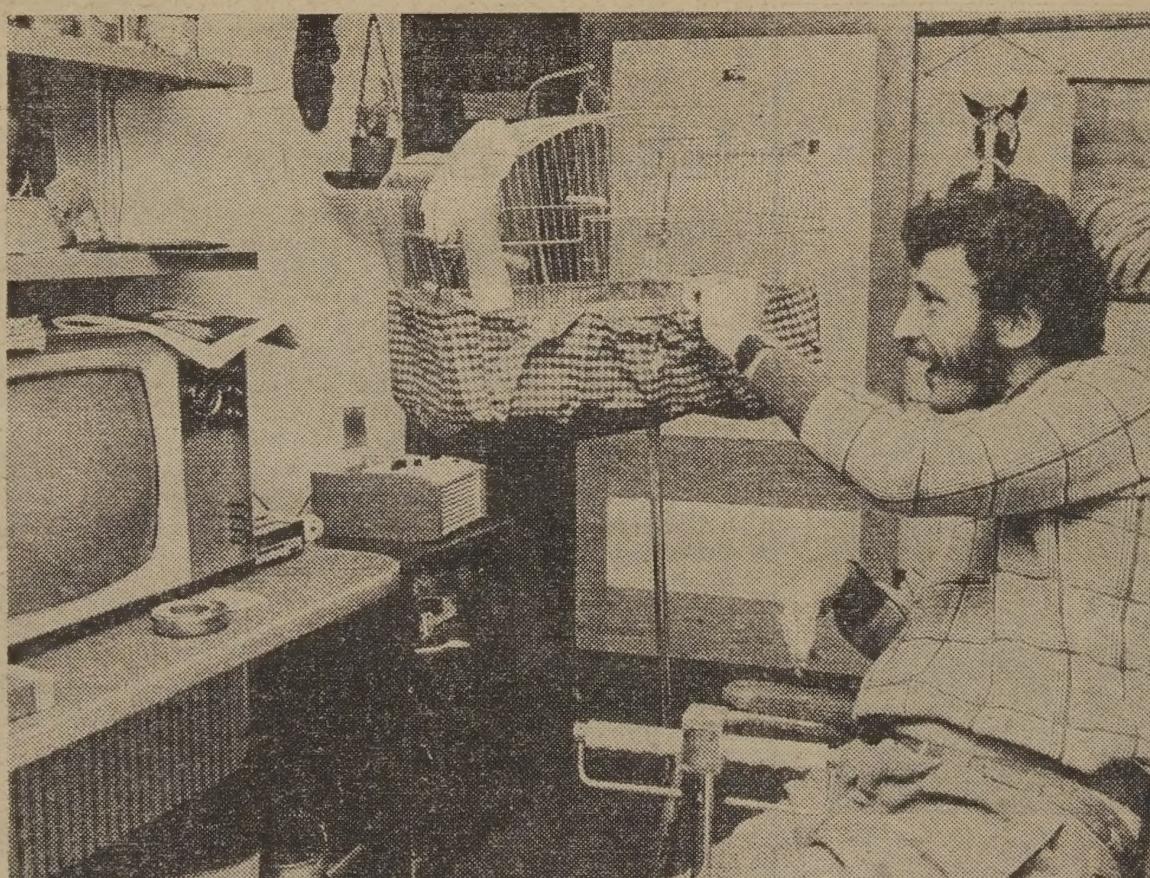
have problems with unadapted equipment in their science laboratory. Jonathan has been spending several hours a week at the school investigating the special needs of the science students.

Clive has been looking into the possibilities of designing an effective page-turner, and has been studying available models in order to design something with fewer drawbacks.

**PICTURE shows the Prince of Wales listening interestedly as 18-year-old CSV volunteer Clive Waters explains his design project.**

Picture by Joe Bulaitis

## Happiness is . . .



• . . a pet of your own in a cosy bed-sitter of your own. Laurence Turbayne is pictured — with feathered friend — at The Spastics Society's Princess Marina Centre in Buckinghamshire where new extensions have given even higher standards of comfort and privacy to the handicapped residents. Story on Page 5.

## Esther's rose helps funds bloom

TELEVISION personality Esther Rantzen has requested that sales of the new rose, named 'Esther's Baby' after her daughter Emily, will help The Spastics Society. The new rose, a sturdy red miniature bloom, will make its debut at the Chelsea Flower Show this month.

The rose has been developed by the world-famous growers R. Hark-Hertfordshire, which celebrates its centenary this year.

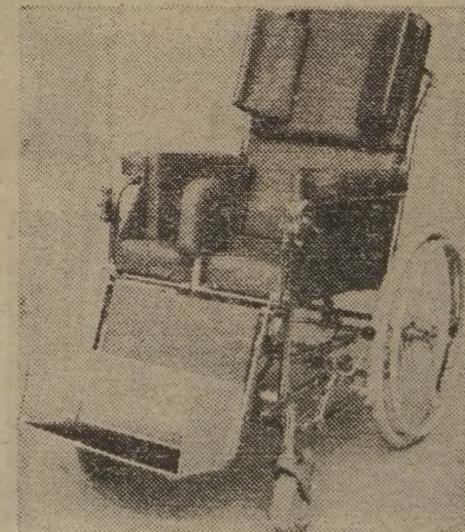
Cont. on Page 2

## Government pledge on 'Save a Baby' study

'A CONSERVATIVE government will ensure that the Commons' study, nearing completion, of perinatal death and handicap being undertaken by a sub-committee of the Select Committee on Expenditure, is completed and its report published.' That was the pledge made—just before the election—by Mr Patrick Jenkin, MP, and it is especially important now that he has been appointed Social Services Secretary by Mrs Thatcher.

We shall see that the work is finished either by the sub-committee itself or by some equivalent committee, said Mr Jenkin, adding: 'I regard this as a most important piece of work and I know that the professions and other interests concerned will welcome this pledge.'

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SN May 12



## Disarming the Colonel

WHEN it comes to knitting manoeuvres no one can pull the wool over Pat Carthy's eyes — she is the purl and plain expert at the Stars Organisation for Spastics' Wakes Hall Centre, as Lt-Col Dennis Williams discovered when he made a recce there.

He is the new Colonel of the 47 Field Regiment at Colchester and it was his first visit to the centre

which is the Regiment's adopted charity.

When it comes to knitting machines, Lt Col Williams was on unfamiliar territory but he soon found an ally in Pat who willingly showed him how to run up an alternative to his olive green combat gear.

Picture by Essex County Newspapers Ltd

Rubella protection—it depends where you live

# Survey reveals 'shocking' facts on baby-saving vaccinations

**SHOCKING** variations in the availability of vaccination against rubella (German measles) for schoolchildren and women of child-bearing age have been revealed in a nationwide survey compiled by The Spastics Society.

The report is being sent to every community health council and area health authority in the country urging them to review their provisions in the light of the figures on their performance, and to make rubella protection a priority in the coming year.

The report points out that if German measles is contracted during pregnancy it can result in the baby being born totally deaf, blind, or suffering from severe mental and physical handicaps. The risk of the birth of a handicapped infant is about 50 per cent if the mother contracts the virus in the first month of pregnancy, 20 per cent in the second month and 7 to 8 per cent in the following eight weeks. If caught in early pregnancy, rubella can also lead to miscarriage or still births.

In Britain, between 200 and 300 rubella damaged babies are born every year and the figure in 1979 will be considerably larger

following on the 1978 epidemic.

A programme for vaccinating schoolgirls against rubella started in 1970. But the report demonstrates that the programme has failed consistently to achieve a reasonable cover for schoolgirls. Figures quoted for area health authorities throughout England and Wales showed that only a 'paltry' 2,802 more vaccinations had been achieved in 1977 as compared with 1976; and that regional variations were wide. For example, the Society's survey estimates that Rotherham vaccinated 61 per cent of schoolchildren in 1976 and only 36 per cent in 1977, compared with Suffolk which achieved 100 per cent and 88 per cent. Rochdale, with its high perinatal mortality rate, achieved

only 22 per cent in 1976 and 63 per cent in 1977, compared with Bedfordshire's 87 per cent and 99 per cent.

Sixteen area health authorities who failed to achieve a vaccination rate above 65 per cent in either 1976 or 1977 are named. They are: Gateshead, Calderdale, Barnet, Ealing, Redbridge, Rotherham, Brent/Harrow, East Sussex, Hampshire, Isle of Wight, Coventry, Dudley, Bury, Oldham, Rochdale and Trafford.

### Private schools

The report also examines the position in private schools and concludes that as many as 20 per cent have no routine programme of vaccination. Of the 80 private schools replying to questions, including some of the best known schools in England, 14 had no programme.

It finds, too, that facilities for rubella vaccination among adult women present a 'haphazard and depressing' picture.

The report says that general practitioners vary enormously in their attitude to rubella vaccination. Most do not seek out candidates for vaccination but wait for informed patients to ask. Even then some will not do the necessary blood test because they receive no

fee, yet they offer no alternative solution.

Family planning clinics, in theory, could provide screening and vaccination for women. Here, research showed that the encouragement given to provide such facilities had been heeded by only eight out of 97 clinics. Thus, in over 90 per cent of the country, the opportunity of testing as many as 50 per cent of women is being wasted. This is a scandalous situation and one that the Department of Health should remedy at once,' says the report. It would seem that possibly only eight area health authorities in England and Wales offered routine screening for rubella in their family planning clinics.

## Save-a-baby campaign

Cont. from Page 1

The International Year of the Child Committee has already promised £50,000 which is to be spent in Liverpool where a programme has already been agreed which involves health education as an integral part of the campaign.

And Liverpool is just one of the 10 local campaigns which are in the planning stages, with the campaign resolving with university and local health authorities, checking how far local priorities fit into the national pattern of the campaign. The other areas where there will be public campaigns launched in the autumn include Newcastle, Bradford, South Manchester, Rochdale, Birmingham, Wolverhampton, Bristol, the East End of London and Cardiff.

In Cardiff the fundraising has already begun with the launch of a £100,000 appeal at a reception at the City Hall. Proposals are now being put forward by Professor Brian Hibbard of the University of Wales as to the medical objectives. What is exciting, according to Michael Brophy, is the drawing together of these different sections of the community towards a common goal.

A similar event for prominent businessmen took place in Bristol on April 5 presided over by the Earl of Westmorland, when Dr Peter Dunn, of the Department of Child Health, Southmead Hospital, was the main speaker on the perinatal mortality rate. This is the way we are going to get our yearly target of £200,000 in the second year, comments Michael Brophy. The Society's second 'Save a Baby' film will be launched later in the year.

### Award man will communicate

MR Kenneth Smith, winner of The Spastics Society Achievement Award for 1979 will be amongst the panel of speakers at the one-day conference organised by the Friendship Group of Charities in June.

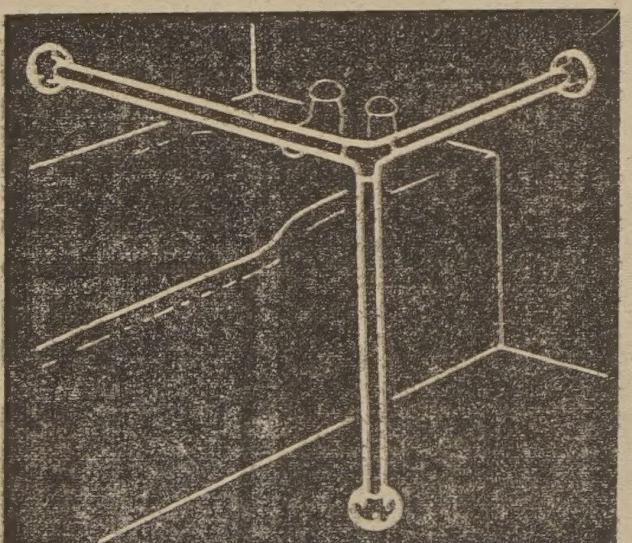
'Communication — A Key to Living' is the theme of this year's conference to be held at the Bloomsbury Centre Hotel on Tuesday June 5.

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SN May 10

## Letter of the month 'How do I cope with this problem . . . ?'

MY name is Carol Cartwright, and I am suffering from cerebral palsy. I am writing to you with the aid of a head band and an electric typewriter as I am quite physically handicapped.

I would very much appreciate having my letter published in Spastics News of which I am a regular reader. Often I am thrilled to read good news through the columns of Spastics News and very often I rejoice with the achievements and success stories that are very often featured in the paper.

However, my story is just the opposite. I live in the Barnsley area in a council house on which my parents have recently spent more than £1,000 on adaptations, etc., to make our home suitable for a wheelchair, as I am confined to spending all day in the chair.

My mother is a diabetic and suffers from angina and weighs just 6½ stone. So my father has to do most of the lifting as you can well imagine. We applied to social services to see if they could help us with the cost of a chair lift. They turned us down flat and so my father continues to carry me up and

# Spastics News visits a friendly school in Devon



BILL and Ben are delighted to have passed their 'driving test' on Batic cars, thanks to a practice track in the grounds. The over 16's who have taken part in the school's mobility programme can then use the cars outside when they go to the PHAB Club in the village nearby.



THE physiotherapy department makes use of therapy rolls which can be taken home in the holidays so that parents can help with treatment.

## Long tradition of meeting special needs

MANY parents who don't want to send a young handicapped child away to a residential school recognise the benefits of an education away from the family for a 16-year-old, says Roger Huxtable, headmaster of the Dame Hannah Rogers School at Ivybridge, Devon.

The school, which is affiliated to The Spastics

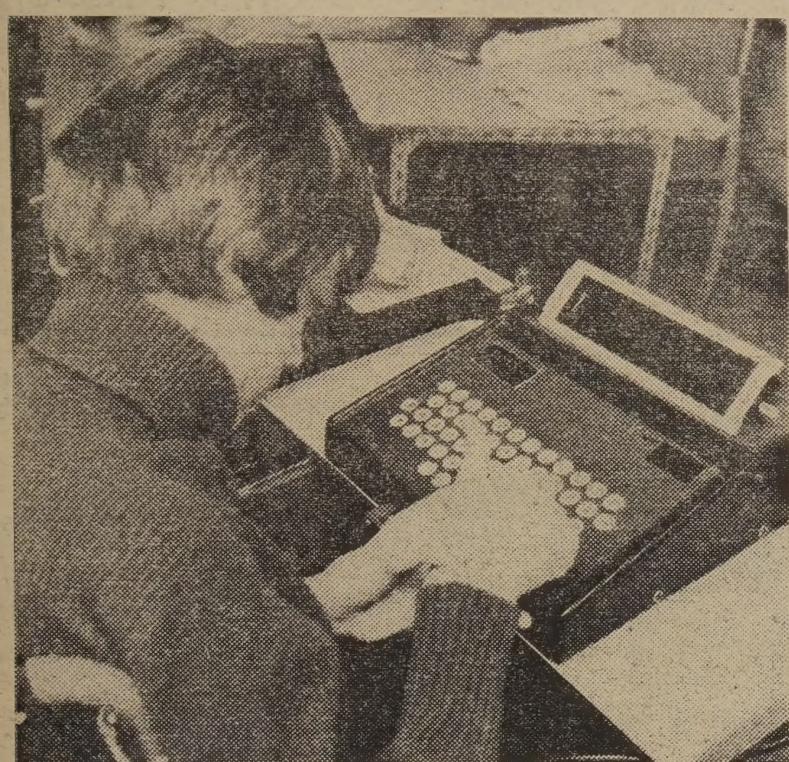
Society, provides a general education for all categories of handicapped children from five to 19 years of age, with various options such as weekly or full-term boarding — some children even attend on a daily basis.

However, the special emphasis at Dame Hannah Rogers on arts, mobility and independence makes the school particularly suitable for the over 16s. As well as encouraging their own children to stay on after 16, it is now the school's policy to welcome other handicapped teenagers from anywhere in the country to come and share their superb facilities — small classes, especially for music, as well as readily available intensive speech therapy and physiotherapy. And for someone brought up in the city, there is the opportunity to experience a taste of outdoor life in the Dartmoor National Park or on the South Devon coast.

This forward looking focus on the future needs of the handicapped adolescent is typical of the flexibility of the Dame Hannah Rogers Trust, which has a long tradition of meeting special needs.

**LEFT:** Kathy works at the Possum in the physiotherapy room while she learns the functional movements. Says physiotherapist Mrs Alexander: 'We concentrate on hand movements as a top priority. After all, it's hands that work the Possum and other communication aids.'

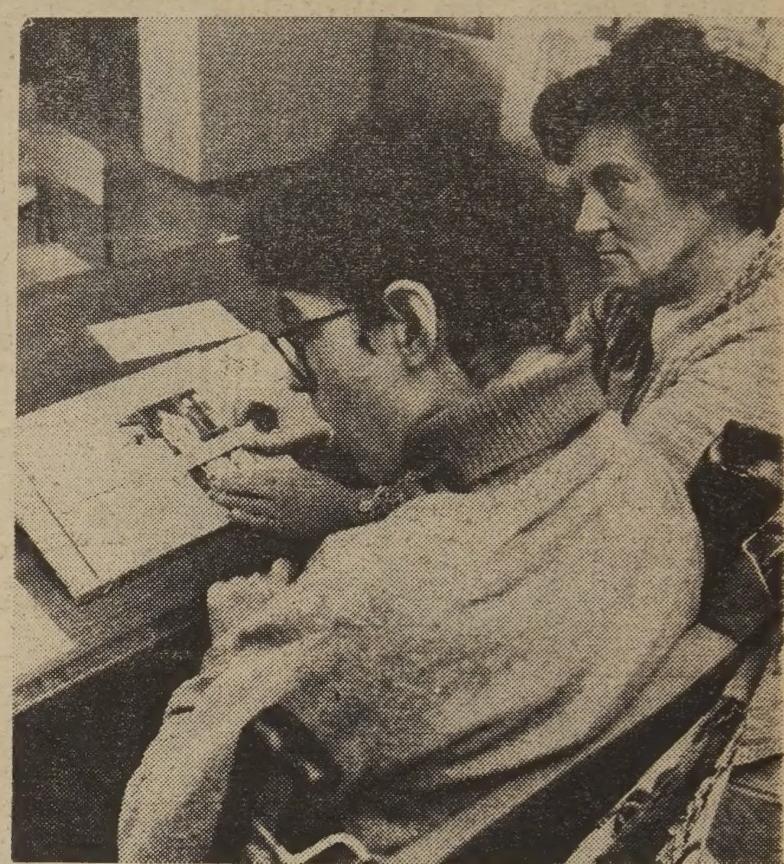
**BELOW:** Speech therapist Mrs Jean Bolton (centre) has been at the school for seven years. With a pupil ratio of 1 to 13, she's able to concentrate both on individuals as well as working imaginatively with groups in the classrooms. Here the children are busy recording their own radio programme.



MANY students without speech use Lightwriters where the illuminated sentences appear almost instantly on the dashboard, giving a tremendous speed-up of communication.



BEN takes great pride in looking after the bird table which he made himself in the woodwork class.



ABOVE: Small classes of six and seven enable teachers to spend additional time, using special techniques, with pupils who have learning difficulties.

**RIGHT:** There is a strong emphasis at the school on education for leisure. A head harness helps Susan with typing and page turning as well as painting.

Dame Hannah Rogers, after whom the school is named, was the wife of a mayor of Plymouth who died in 1766 leaving in her will a sum of money for poor and unfortunate children in the Plymouth and Devon area. The trust fund has been used in various ways over the years and by 1924 there

Cont. on Page 4



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## Probing the role of parents

OVER 170 delegates from all over the West Country will gather at The Spastics Society's West Regional Conference in Queen's Building, Exeter University, on Saturday May 19 to hear experts talking on various aspects of parent responsibility.

The Chairman will be Mr R. J. Bricknell, vice-chairman of North Devon Community Health Council.

Mr James Loring, Director of The Spastics Society, will be talking about 'The role of the husband during a wife's pregnancy'; Mr Alastair Mackie, Director General of the Health Education Council, will speak about 'Cradle and All'; Mrs Lorna Bailey, lecturer in Health, the Open University, will speak about 'Learning to be a parent — can the Open University help?'; Mr Michael Brudenell, consultant obstetrician and gynaecologist at King's Hospital, London, will speak about 'How to have a healthy baby.'

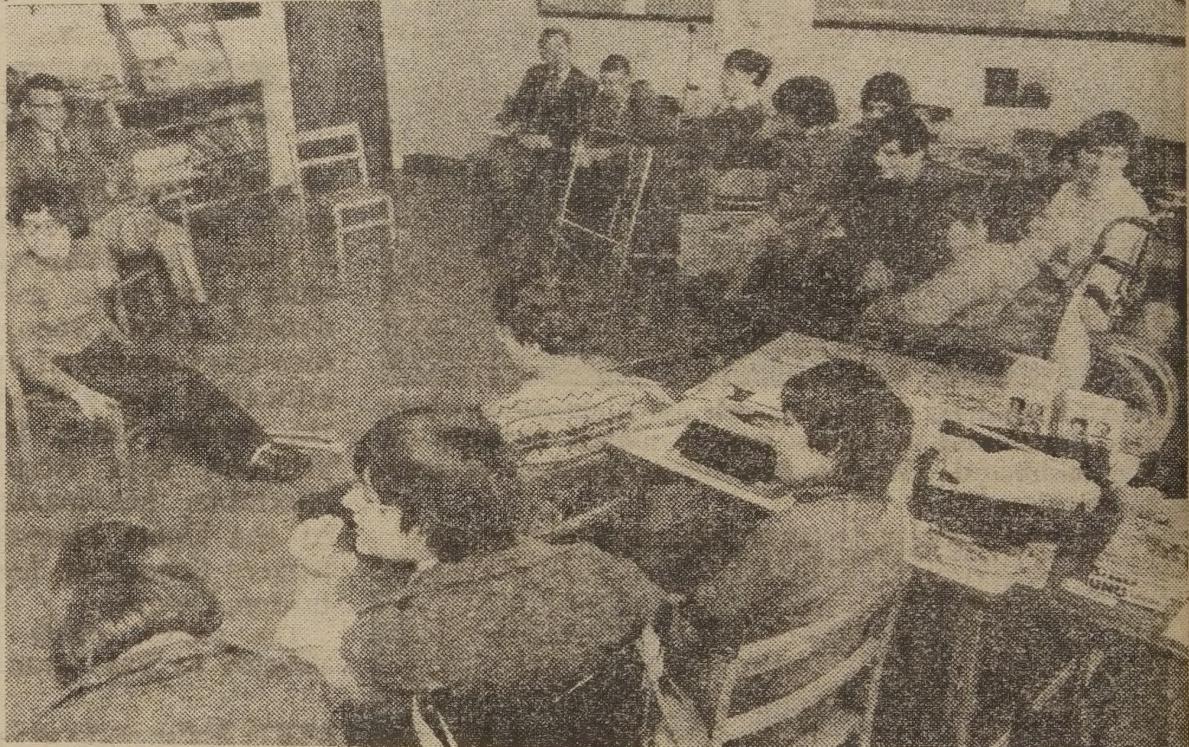
similar to techniques used in human behaviour modification. As well as being taught to turn knobs and push buttons, their trainer believes that they can also learn how to feed a disabled person and help with grocery shopping.

Crystal can already turn on the radio and TV set, and pick up small articles from the floor, as well as opening the door for visitors.

There were initial problems in funding the research project with would-be sponsors proving as sceptical at first as Crystal's master, a 31-year-old quadriplegic computer programmer.

Capuchin monkeys are found in South Africa, and only the female of the species has been used in the experiments because they are more gentle and affectionate than the males.

Crystal and another capuchin monkey were trained by a method of punishment and reward



THE regular Friday debate provides a lively session of differing views from all sides regardless of speech handicaps. One of the pupils always takes the chair. This Friday forum proved a valuable training experience for a recent local public speaking contest where three of the pupils competed with outside clubs, a remarkable achievement for a school where half the pupils have initial communication difficulties.

## School's long tradition

Cont. from Page 3

was an Orthopaedic Hospital School, the first of its kind in the south-west. By October 1949 the school buildings, altered and adapted, were opened for the reception of 27 spastic children, again a pioneering project for the south-west, and only the fourth establishment of its kind in the country.

A 1953 Coronation Appeal boosted by Round Table funds resulted in the building of the existing school with room for 50 children. A substantial Ministry of Education grant was made available and the remaining money provided by the then National Spastics Society.

Over half the pupils have communication difficulties and several have no speech at all. Yet particularly noticeable to an outsider visiting the school is the obvious desire of everyone to communicate. At the regular Friday debate pupils without speech keep their Lightwriters busy making their opinions known and how-

ever heated the argument, incredible patience is shown by the others.

The ultimate in local participation is the annual Ten Tors expedition on Dartmoor, organised by the army each May, when the Dame Hannah Rogers School is the only school for physically handicapped youngsters to take part.

Preparation for this quite physically gruelling expedition, which involves spending a night under canvas, includes a talk on survival by a Dartmoor Rescue Officer who gives a briefing on the whistle distress signals; a demonstration of how to change a tyre on a wheelchair, plus numerous 'toughening up' practice trips. The Ten Tors expedition isn't just an outdoor exercise however; also involved are skills like map reading which are a classroom activity as well.

In a small friendly school like Dame Hannah Rogers, it's hard to define clear boundaries between classwork and therapy. Speech therapist Mrs Jean Bolton often works alongside the class teacher, while Mrs Elizabeth Alexander, responsible for the physiotherapy staff, comments: 'We're school physios, not just physios. So

we concentrate on hands as our top priority — after all it's hand movements that work the Possum and the Electraid and the other means of communication.'

For the over 16s in wheelchairs, who would formerly have been issued with the three-wheeler trikes, which have now been withdrawn, there is a mobility programme learning to use Batrie cars. A practice track in the grounds provides experience before doing the proficiency test which the school has devised. So while the able bodied members of the PHAB Club in Ivybridge, run by a former physiotherapist at the school, come along on their motor bikes, the Dame Hannah Rogers members can cruise along independently in their Batries, without having to be transported by minibus.

Yet another innovation for the older pupils will be the forthcoming conversion of a self-contained flat on the site, once occupied by a caretaker, so that small groups of four or five can experience cooking and looking after themselves.

Nancy Tuft

## Dogs help the blind — can monkeys aid the disabled?

# Surgeon is new chairman of Scottish Council

A SCOTTISH surgeon with a world-wide reputation as an orthopaedic specialist, has been elected chairman of the Scottish Council for Spastics.

He is Mr George Pollock, MS, FRCS (Ed & Glas), FACS, DPH, of Kirklands, Melrose, who has been associated with the Council almost since its inception. He has been a member of the Executive Committee since 1948 and vice-chairman for the past 10 years. He succeeds the late Mr Archie McConochie, JP.

A graduate of the Medical Schools of Glasgow and Edinburgh, Mr Pollock spent five years as a surgeon at the Kobe International Hospital in Japan, using one of his leaves to study in Vienna, then at the height of its



Mr Pollock

fame as a medical centre. In 1936 he became a Fellow and later Assistant Surgeon at the well-known Mayo Clinic in the United States and for the next 4½ years specialised in orthopaedic surgery.

On the outbreak of war, he returned to Scotland to work with the Emergency Medical Service. There he took charge of Peel Hospital, near Galashiels, where he remained until 1945. Subsequently he was appointed Consultant Orthopaedic Surgeon at the Princess Margaret Rose Hospital, Edinburgh.

He is a former chairman of the World Commission on Cerebral Palsy (now the International Cerebral Palsy Society).

Speaking of the Council's future work, Mr Pollock said: 'The Council must increase its

provisions of care, education and treatment for the younger group of handicapped children and of training and work activities for the rehabilitation of the older group. Cerebral palsy is not curable, but with expertise possessed by the Scottish Council and other centres of excellence in Britain, the physical disabilities can be lessened and the whole outlook for sufferers from the condition improved.'

'We know from what has been done during the past few years that the incidence of cerebral palsy can be reduced by 40 per cent and it is more than probable that by improving the care and treatment given to mothers during their pregnancy and at the time of birth, still further reductions are within the bounds of possibility.'

## Emergency appeal saves holiday home

ELLERSLIE Court in Southport, the only holiday home for spastics in the North West, is to stay open, for the time being at least. Thanks to magnificent local support from the community, from Brownie packs to old age pensioners, the threatened close-down in July of this holiday home run by the Southport, Formby and District Spastics Society will not be necessary. . . .

'It's the only place of its kind in the north-west and it would have meant that a lot of spastic people wouldn't have been able to take a holiday at all,' says David Bourne, local appeals officer for the North West Region of the Society, who launched the emergency appeal to save Ellerslie Court.

The appeal target is £20,000 and they are half-way there already. Nearly £10,000 has been raised so far through coffee mornings, fashion shows, raffles, door knocks and appeals to local industry.

'The people of Southport have really rallied round,' commented Nigel Smith, North West Senior Regional Officer for the Spastics Society.

One of the main problems in keeping an establishment like Ellerslie Court out of the red is in attracting sufficient visitors

## A cheque for £12,000 . . . • Now you see it • Now you don't!



LORD Parry presents the cheque to Michael Brophy, The Spastics Society's Director of Fund Raising. Then, as you can see in the second picture, a moment captured by the South Wales Echo, Michael tore it up! Explanation in story below.



## Michael's ripping idea

AN evening of high drama and hard fact marked the launching of the Cardiff 'Save a Baby' campaign in the City Hall.

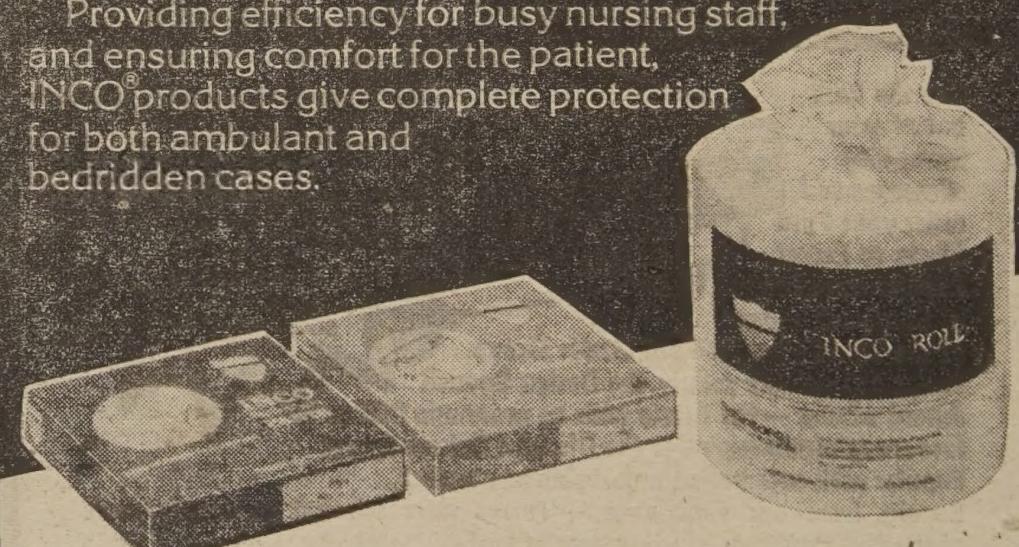
The appeal was opened by the President of the Wales Region, Lord Parry, who explained the history of the 'Save a Baby' campaign in the Principality so far and the targets still to be achieved. He then introduced Professor Brian Hibberd, Professor of Obstetrics at the Welsh National School of Medicine who talked of the real problems that exist in ante-natal care and the recommendations of how perinatal death in Wales, particularly Cardiff, could be reduced.

Lord Parry presented a cheque for £12,000 to Michael Brophy, the Society's Director of Fund Raising, as the Welsh contribution to the Society's campaign fund. Mr Brophy took the cheque and to the undisguised horror of the hall, crowded with Spastics Society members, representatives of industry, unions, local authorities and the medical profession, tore the cheque into four.

However Mr Brophy's explanation was rapturously received—he said the £12,000 was a donation from The Spastics Society to the Cardiff 'Save a Baby' appeal fund. His message was that if other people in the city were to follow his example the raising of £100,000 should be surprisingly easy.

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## New Parliament will hear campaign petition

IT is just a year since the 'Save a Baby' campaign signature petition demanding a better deal from the government for Britain's babies was launched. In that year almost a million signatures have been obtained and this month sees the petition presented to the House of Commons.

It will be the culmination of 12 months hard labour by devoted voluntary workers, dedicated professionals, housewives and stars, all

of whom have contributed their services in some way to ensure the petition's success.

The signatures on the petition come from every corner of Britain and all types of people. Union leaders and industrialists, city worthies and entertainers all put their names to the plea for more government aid to ensure babies are born alive and healthy.

One of the first duties

## FOCUS ON FUND RAISERS

HUNDREDS of events to raise money for spastics are taking place every month, and shortage of space means that Spastics News can only mention a fraction of them. A pity — because so many of the ideas are so novel.

Here are some of the latest we particularly liked.



### Batting . . .

KEVIN Whitehorn had a batty idea to raise money for spastics — non-stop games of sponsored table tennis. No wonder he began to see ping pong balls before the eyes after playing from 8 pm on the Friday evening right through till Saturday lunchtime. The 16 hour marathon match arranged by Kevin was played in half hour sessions by the members of the Twickenham Youth Activities Centre. Proceeds went to the Stars Organisation for Spastics.

Picture by the Evening Mail, Slough

### A fling in Ali's garden

PEOPLE walking past Ali Mustafa's garden in Holloway, North London, just could not resist having a fling. For in Ali's garden was a magnificent ornamental pool and passers-by really splashed out when it came to throwing coins. It gave Ali an idea for fund-raising and from a small pool a fountain of generosity has sprung up.

Last year Ali gave £1,600 that he had collected to The Spastics Society. The money came from pubs in a wide area in North London and now Ali has set himself a new target — £12,000 for a new ambulance for the Hornsey Centre for handicapped children at Muswell Hill.

### Racing . . .

'THEY'RE away.' Members of Tring Ladies Circle were under starters orders at a charity race night meeting held in aid of the Society's 'Save a Baby' campaign.

The 150 guests at Pitt-stone Village Hall studied the field beforehand, and then sponsored the runner of their choice before watching films of seven horse races.

The event was organised by Mrs Janet Mewis and £250 was raised.

Picture by Bucks Herald

### Flowering . . .

HOSTESS Mrs Jean Freer together with Mrs Gillian Gadsden, chairman of Leicester Ladies Guild raised £200 recently towards the Society's 'Save a Baby' campaign by holding a floral 'at home.'

Every single room in

Mrs Freer's large house boasted a wonderful display of flowers and in spite of a wet day, there was huge turn out of visitors. Members of the public came in two sessions, morning and afternoon. As well as serving morning coffee and afternoon teas to the visitors, the Flower Guild ladies also had the job of cleaning up after all those muddy boots!

And if their daytime efforts weren't enough, in the evening there was a wine and cheese party.

Picture shows Mrs Gadsden pointing out a special bloom to Mrs Freer.

Picture by the Leicester Mercury

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# MOTABILITY

SN May 15

### Hopping . . .



HOPSCOTCH in the playground of Chapel Primary School, Colchester, raised £6.10 for spastics as well as providing instant entertainment for the rest of the school. Mrs Monique Chapleo of Wakes Hall Spastics Centre later called at the school to thank the five ten-year-old youngsters who thought up the original idea of hopping for a good cause.

Picture by Essex County Newspapers Ltd

### Exotic gifts boost auction profits

A TIBETAN gold amulet studded with turquoise and donated by the Dalai Lama, together with a mother of pearl jewellery case from King Hussein of Jordan, were just two of the more exotic items put up for auction recently by the St Austell and District Spastics Society. The amulet fetched £160 and the jewellery case £200, while a headscarf and signed photograph given by Mrs Margaret Thatcher raised £32.

The auction, held at the New Cornish Riviera Lido, Carleton Bay, raised over £2,000 and the top price for any one single item was the £300 bid for an antique silver inkstand donated by the auctioneers themselves,

Robin Barlow, and Brian Bearne of Sotheby-Bearne.

The Mayor of Restormel, Mr William Hosking, started off the bidding with a tankard won by the late Graham Hill and donated by his widow Bette Hill. This went for £21, while a James Hunt racing driver's fireproof suit fetched £82. An Annigoni red chalk drawing was sold for £145.

The organiser of the auction, Mrs Amorell Williams, said that the first £400 of the proceeds would be used to send 10 of the group's people for a week's holiday to the Society's Field Study Centre at Lanhydrock.

THE UK John Denver Fan Club raised £81.47 towards the 'Save a Baby' campaign by means of a draw which took place at the recent John Denver concert in Manchester.

PROCEEDS from the sale of record by the Cheltenham group Decameron are helping spastic children. The group called 'Save the Bayhill' is protesting against the possible closure of the Bayhill Inn, Cheltenham, because of a new ring road being built.

A SPONSORED fancy dress pram race through Cranbrook brought in more than £100 for the Cranbrook and District Spastics Appeal Fund. The pram race took place on Sunday lunchtime when the main street was closed to traffic for the occasion.

Twenty-one out of 24 contestants completed the course and only one pram collapsed under the strain! Winners a group from Staplehurst completed the course in minutes, winning a holiday for four in the Channel Isles.

THIS year's Fitzroy Fair will be held on Thursday July 6 from 6 pm till midnight. Capital Radio's Fun Bus will be there, plus stars of TV and stage, and other attractions.

Anyone interested in taking a stall should contact Ian Sturmy at The Spastics Society's Family Services Assessment Centre, 16 Fitzroy Square, London W1. Tel: 01 387 9571.

# Their new homes within a 'home'

## Residents enjoy new independence

NEWLY-opened extensions at The Spastics Society's Princess Marina Centre in Buckinghamshire mean that all 54 residents can now enjoy the privacy of separate bedrooms. In some cases the innovation has come after 16 or 17 years of shared sleeping quarters, and there is widespread delight at the new arrangement.

**Mary and David Harris are one of five married couples living at the centre.** Both in wheelchairs, they have a ground-floor bed-sitter in the refurbished old house, known as 'Ponds.' Probably one of the original reception rooms, it is elegantly proportioned with stone-framed windows and lightened by furniture in pale wood. A curtain can be drawn to separate the sleeping from living area.

David has been at the centre since 1955 when it

was run by the British Council for the Welfare of Spastics. This body amalgamated with The National Spastics Society in 1962 to become The Spastics Society which has administered the centre ever since.

Mary came to the centre in 1965, they married in August 1976 and moved into their present quarters last July. Both are reading for Open University degrees and as a traveller on the OU's first trip to Rome organised for disabled students Mary contributed to the subsequent book 'Have Wheels, Will Travel.' Later this year both she and David hope to join a similar tour to Greece. With their intensive university study programme they value the seclusion and tranquility of their own room.

Said David: 'It's far enough away from the main stream for us to be able to forget that we're living in a residential centre...'

'But there are plenty of activities we can join in if we want to,' added Mary.



• MARY and David Harris — one of the five married couples at the centre — are pictured in their spacious bed-sitter; cosy, comfortable, cluttered, a real home.

They join the other residents for main meals in the communal dining room, but have facilities for making their own tea and coffee. They also prepare supper for themselves on Sundays when many of the staff are off-duty.

**Altogether 25 new bed-sitters have been made available at the centre, some in the converted 'Ponds' block, others in three purpose-built units named after trees. The Spastics Society paid for the building work and structural alterations completed in July 1978, while the Friends of the Princess Marina Centre provided 'extras' such as floor-coverings and curtains.**

All the rooms and covered passageways linking the various sections have carpet tiles in glowing shades of brown, gold, claret or moss green which diffuse an atmosphere of warmth on the dullest day.

**Bridget Smith, who drives an electrically-operated wheelchair lives in the 'Cherry' area in a bed-sitter leading off a small sitting room shared with four others.** A french window opens on to the paved area surrounding the house, giving immediate access to the spacious grounds.

Communicating lucidly by means of a letter and word board she designed herself, she said she had been at the centre for 18 years, after leaving the Society's Craig-y-Parc

School in Wales. This was the first time she had had a room of her own, but she said she did not miss the company of others.

Like other residents, Bridget spends some time in the workroom each day and attends adult education classes. Her chosen subjects include English, history and natural history. In her own room she listens to the radio a good deal. She enjoys all kinds of music, especially folk.

**The Lime area is inhabited by a married couple**

and three single residents. One of the latter is Laurence Turbayne, now in his 18th year at the centre. Before moving to his own quarters he shared a bedroom with four others, and he says that the new-found privacy has already made him more independent.

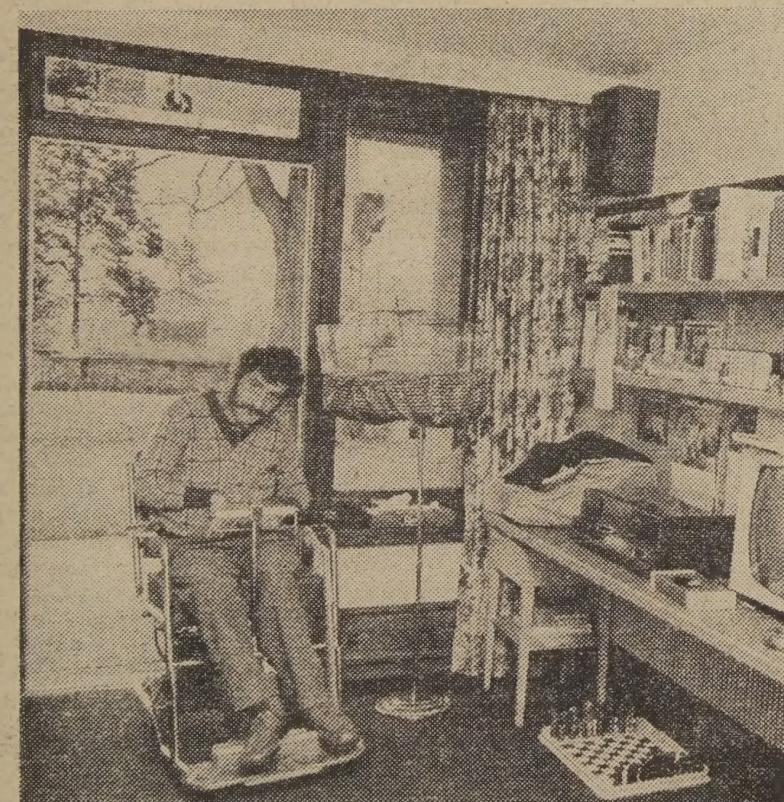
'The best thing is being able to get up and go to bed when I like,' he said. 'When the staff had five of us to get ready, they found it was quicker to help us with our clothes, but now I find I can take my time

over dressing and undressing myself.'

Although he uses a wheelchair to move around, Laurence can stand unaided. This means he is not forced to rely on staff for the transfer from wheelchair to bed and back again. Like Mary and David Harris, Laurence rents his own television set and now there are no room-mates to consider he is able to keep a budget.

He said: 'I've visited

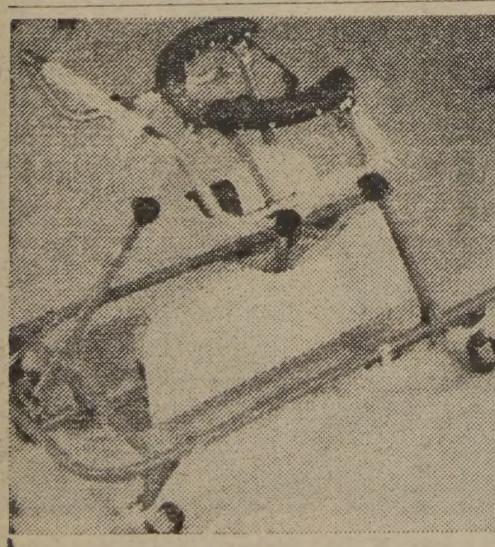
Cont. on Page 10



• LAURENCE Turbayne — pictured with his budgie on the front page — values the independence provided by his bed-sitter.



• BRIDGET Smith enjoys the privacy of her own bed-sitter, beautifully furnished and appointed. The french windows give easy access to the grounds.



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## DELEGATES MEET



**AN academic trio of headmasters, whose pupils range from the most severely handicapped to the very gifted. George Marshall, left, of Dene College and Pat Mayhew of the Thomas Delarue School, both Spastics Society establishments, chat to Brian Piggott of the Valence School, Westerham, Kent, at the Oxford seminar.**



**PHILIP Herriman talks to Dora Vourloumi, one of the delegates from Greece. Mr Herriman, teacher at a large comprehensive, was one of the seminar speakers.**



**PORtUGUESE delegate Jorge Casimiro chats to David Heptonstall, headmaster of the Frank F. Harrison Comprehensive School, Walsall.**

# Jobs, homes, choices . . . probing the prospects for school-leavers

**Leaving school in the 1980's—a seminar held at University College, Oxford — a personal view by Anita Loring**

This is the 13th meeting I have organised at Univ. and over the years I have come to realise that they all have at least three things in common: the first is most people usually complain of the cold, an occupational hazard for any conference organised at Oxford around Easter, the second is that one particular theme emerges from the papers, and the third that there is always a point of conflict where if participants don't actually assault each other during the discussions they make secret assignations for the College bar that same evening.

**Geoff Bushy** gave the opening paper entitled simply 'Leaving school in the 1980's.' In his view three questions are fundamental to what life is going to be like for the school leaver in the 80's:

What do I want to do with my life?

How best can I fit myself into society in order to achieve that end?

How to decrease the number of 'man-made' obstacles that are increasing a handicapped person's handicap?

### Struggle

For Geoff Bushy, like many other people leaving school, obtaining appropriate further education, finding a job and suitable accommodation had been an uphill struggle, but throughout his paper he was uncompromising as far as handicapped people are concerned, they must develop their own individuality, and not expect too many favours. Above all, he felt that the greatest contribution that society can give a disabled child is to create an environment into which the integration of the disabled would be normal, provide as many opportunities for him as possible and promote the idea of self-help.

**John Wilson**, an Oxford philosopher like Mary Warnock, talked of three fashion-

able fantasies, these were to suppose that what we in a particular society count as 'handicap' corresponds to what it really is to be handicapped in the important goals of life; that education of character — as he put it, the soul — is at least as important as the development of intellectual understanding; that it is a fantasy to suppose that a person is 'getting an education' just by attending courses and passing exams, and thirdly to suppose that educational development need not involve success and failure. He pointed out that nearly all modern educational institutions in 'liberal' societies are hopelessly amorphous and chaotic; they allow students to acquire some skills, but make no serious attempt to educate them as people. John Wilson's paper was referred to, continuously throughout the meeting, his handicaps were also identified first as not knowing his left from his right, and a pathological incapability to speak slowly — particularly necessary for the foreign guests! The main theme was beginning to emerge.

**Jean McGinty** and **Freddie Green**, two HMI's from whom I derived much of the inspiration for this meeting, gave a comprehensive view of the various developments and pioneer projects current in further education for the handicapped today, many of which were to be talked about in more detail later in the meeting, and the implications of the Warnock report on the transitions from school to adult life respectively. Much has already been written about this important document, but one of the main recommendations finding considerable favour is that every student should have a 'named' person to refer to who would guide them along the thorny path of transition from school to whatever appropriate placement they follow.

The first important step for the school leaver is in careers advice and counselling. David

**Heptonstall** and **Philip Herriman** from a large comprehensive in Walsall described how



**GEOFFREY Bushy** is a computer programmer who opened the seminar's packed three-day schedule with his talk which embodied the seminar's title: 'Leaving school in the 1980's.'

they had dismantled a conventional careers advice system in favour of a team of teachers drawn from throughout the school who were able to give a wide variety of advice, much of it based upon work experience courses which they themselves had been on. **Philip Dyer** of The Spastics Society described how their own careers officers visited the children within their school helping to plan their future placement.

### Rumblings . . .

Much discussion followed these two papers and the rumblings of conflict were very faintly heard.

**Ray Overland** from Australia read a paper prepared by an old friend who has made many contributions both in person and by proxy at our Oxford meetings, **Geoffrey**

**Swan**, an HMI from Queensland. His overview led him to conclude that the narrow focus on a specific handicap is no longer tenable. Community awareness, acceptance, and the realisation of potential are now real expectations and aspirations, and no longer pious hopes for the handicapped. From 13,000 miles the same theme which was further echoed by **Brita Sjögren** from Sweden and **Gerald Cornelissen** from the Netherlands. He emphasised not only the objectives, but the possibilities and impossibilities that exist for handicapped people which must not and cannot be denied.

### Hostel

There followed three sessions during which two speakers each spoke on the same subject but from a different approach. **Alan Gait** — tutor in charge of the unit for handicapped students at the Bridgend College of Technology has recently opened a hostel situated within the College grounds where handicapped students live whilst following courses at the College. This is an imaginative attempt both to provide for the special needs of handicapped students whilst not depriving them of the experience of learning alongside their able-bodied peers.

By contrast **John Hall** of The Spastic Society's Dene College emphasised the way in which his new course strove to make students, some of whom have quite a degree of mental handicap, responsible for their own lives by being encouraged to make as many decisions as possible about what they wish to do — to the extent of being allowed to decide not to do anything at all during certain unstructured parts of their programme. How often are we all too anxious to ensure that every minute is filled with something 'worthwhile' when all the individual may want to do is absolutely

**Cont. on facing page**

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SN May 13



**JOHN Boyle, Peter Lowe, Ken Dixon and Alastair Kent share opinions, ideas and anecdotes over a cup of tea. Speakers were drawn from England, Sweden, Holland, Australia and the USA, giving delegates an invaluable opportunity to swap experiences.**

# International view at Oxford



AJLAN Al-Ajlan of Saudi Arabia in discussion with Mr A. M. Macpherson, head of Lord Mayor Treloar Upper School, and Ray Overland, educational psychologist to the Queensland Department of Education.



KLAUS Kiesenthal from West Germany talks to Mike Curoe from the United States of America. In the background is Edward Doherty, principal of the Society's Oakwood centre.



PART of the Swedish contingent take a refreshment break during the course of the busy seminar. From left to right they are Bjorn Rundstrom, Brita Sjoqvist, Angela Rundstrom and Bo Ingberg.



FREDDIE Green and Jean McGinty both of Her Majesty's Inspectors, flank Betty Adams of The Spastics Society. Both Miss McGinty and Mr Green delivered papers at the seminar.

## Robbery inspires good turn

YOUNG Steve Frixou was horrified when his parents' fish and chip restaurant in Chaddesden, Derbyshire was robbed of a full Spastics Society collecting box so he took immediate action. He invested his pocket money in two bottles of wine and a box of chocolates, and organised a raffle which made a handsome £23 for the Society.

The local collector said: 'It is nice to hear of something like this in this day and age of stealing and vandalism.'

## Leaving school . . .

Cont. from Page 8

nothing. Knowing how to organise spare time is an essential part of growing up.

Peter Lowe from Hereward and Howard Brayton, organiser of an assessment and work preparation course for handicapped students at Trowbridge Technical College, discussed further education opportunities for the handicapped school leaver. Here were two very different settings. Hereward a purpose-built college for the handicapped school leaver and Trowbridge an integrated course as at Bridgend. The arguments centred around the pros and cons of integration, and Peter Lowe attempted to calm the obvious antagonism growing between the school teachers on the one hand who saw their life's work in the field of special education coming in for criticism, from those convinced that it was possible to place even the most handicapped student in the ordinary sector of further education provided that they had been sufficiently prepared socially to be able to cope. Again the theme, the importance of educating the whole person.

### Training

Gerald Browne, a visionary from Bridgend, continued the debate with Ernest Curtis from Sherrards, who described the successful programme run there for many years to train the severely handicapped cerebral palsied for industrial placement. Gerald Browne

took a much deeper look at the malaise of the education system as a whole. High levels of truancy, boredom and illiteracy, and an interest solely in standing up and actually doing the job as opposed to putting six of something into a plastic bag and stapling it together, had led him to develop a practical work preparation. He believed that one of the major keys to the problem lay in the organisation of an appropriate curriculum, an education programme which would help students to develop confidence, stimulate an urge for further knowledge, encourage worthwhile leisure activities, enable them to make decisions and promote self respect. A subject based curriculum may, however, not be appropriate even in diluted form for the intellectually impaired; an educational programme should aim to produce competent and independent adults and if it fails to do this, then it must be changed.

### Truth

Paul Sommerfeld, the director of the Merseyside community relations council, made most of us feel uncomfortable. He spoke of his work with black minority groups in Liverpool particularly with regard to the difficulties of obtaining employment if you are a member of that group. Does, 'I admire your courage. I do so hope you find your niche in life, but I am afraid we have not a vacancy for you at the moment,' really mean, 'I have not the slightest intention of employing someone like you?'

He left us to draw our own parallels with the handicapped group and the difficulties they experience in obtaining employment.

With the cold at least tolerated and differences discussed further in the bar, the message was clear, whatever you do, develop the whole person, let him decide for himself how this should happen,

### Warning

Perhaps it is appropriate to end with a warning, given by James Loring in one of the opening papers, that unless we follow this all important concept not only do we do the handicapped a great disservice, but there are circumstances in which they can be done positive harm, and once damage is done it is too often very difficult to rectify. His paper entitled, 'the importance of not being earnest' sums up our days at Oxford. Earnest we were, for if a philosophy is worth holding it is worth fighting for, but the problems of the handicapped school leaver must be kept in perspective lest they become accentuated by being taken too earnestly.



## President Carter calls in British aids man

ROGER Jefcoate, consultant on electronic aids for the handicapped, has had a personal invitation from President Carter to attend a meeting at The White House, Washington, on Employment of the Handicapped.

'It's one up for Britain and one up for The Spastics Society,' says Roger, who is also adviser to the Manpower Services Commission on electronic aids in connection with employment.

Roger Jefcoate will be making two round-the-world trips this year, addressing conferences in Japan, New Zealand and Australia. Every year he has the honour of opening and addressing the American Naidex.

'Britain is the world leader in the application of technology,' says Roger. 'Thanks to the NHS we have far greater numbers of people using aids and therefore a far greater knowledge of what works where and how.'

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## Flying away on a pool prize



SPASTICS pool member Joyce Day, from Basildon, Essex, has only been overseas once in her life, and that was to Jersey. Now 48-year-old Joyce and husband James, will be taking a trip to the other side of the world for free.

For Joyce has won an exclusive holiday to Australia and the Far East in a 'Charm Girl' competition for Spastics Pool members.

It was quite a shock for Joyce, when representatives of Top Ten and Qantas, the Australian National Airline, called at the supermarket, where she is chief cashier, to tell her of her success and invite her to a luncheon in Bristol to discuss the holiday itinerary.

The delighted couple will be setting off for their 30-day holiday in October to enjoy the Australian spring sunshine. A final word from Joyce, "This holiday has happened at the right time for us. Our children are now grown up and we will have complete freedom to enjoy ourselves."

Picture shows James (left) and Joyce (right) discussing the itinerary for their holiday with Qantas representatives Mike Carravick and air hostess Deborah Gouorko, who was placed first by the judging panel.



MRS Pat Harvey, of Redlands Way, London SW2, receiving a first dividend cheque for £12,500 from

Mr John Young (left), Chairman of Young and Co's Brewery Ltd, in Wandsworth.

Also pictured, Pat's husband Joe (far right), who has been employed as a lorry driver at the brewery for 35 years; Top Ten's Director Geoffrey Arter and 'Henry Cooper,' who is owned by the brewery and is the tallest Shire horse in England.

### News about the Spastics Pool

MRS Ann Dickson, of Assington, near Colchester, receiving a cheque for £5,173 from Richard Gray, The Spastics Society's Controller of Services, at Wakes Hall Spastics Centre, Wakes Colne, Colchester.

Ann, who has two teenage children, won a double prize on the Spastics Football Pool, a share of the 1st dividend of £5,000 and the 6th dividend of £173.



MR D. Regan, of The Cross, Cheddar in Somerset, receiving a Spastics Society lottery cheque for £1,000 from Mrs Beryl Laver, wife of Roy Laver, Director, Top Ten Promotions. The presentation

took place at the 'Bath Arms,' Cheddar.

The Spastics Society's Instant Lottery has been organised to raise funds for the 'Save-a-Baby' campaign.

OVER 400 spastic and other disabled people from Cardiff will enjoy a day out at Longleat Safari Park this summer thanks to city busmen. Cardiff City Transport's welfare association plan to lay on a convoy of buses for the outing which it is hoped, will be an annual event.

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## End of an era as Britain's oldest spastic dies

THE doctor called to the comfortable South London home of the Butchards for the birth of their first baby on February 21, 1891, shook his head over the puny infant, struggling for life. It had been a difficult forceps delivery and, with regret, the doctor pronounced the child unlikely to survive his first year. If he lived he would be an 'idiot.'

George Butchard, however, was destined to prove the top-hatted, frock-coated medical man wrong. In February this year he was 88, still playing chess, writing short stories and painting. Then in March he had a sudden attack of breathlessness and was taken to hospital where doctors were amazed at his incredibly strong heart. Mr Butchard was ill for just three weeks before his death on April 2, due to bronchial pneumonia.

With his death came the end of a special era for nowhere is recorded a cerebral palsied person living to such a great age, and Mr Butchard was a gifted man, highly intelligent, articulate and alert. Nearly 20 years ago he wrote a series of articles for Spastics News under the title 'Mr Butchard Remembers,' which conveyed a detailed, descriptive and

highly readable account of his life with vivid insight into the world of the middle-class Victorian family.

Mr Butchard was reared by an aunt who had unwavering faith in his very real abilities. He learnt to read and write, but it was not until he was 60 that he went beyond the garden gate on his own.

Mr Butchard remained at home, cared for by his Aunt Maud until her health deteriorated with advancing age, and it was Mr Butchard's turn to care for her.

Then, 13 years ago, he met Ron Eager, a spiritual healer. Mr Butchard found the healing sessions held by Mr Eager to be of enormous benefit. Between them they founded the Blackheath Centre of Healing and Meditation in South-East London.

## 'Homes' of their own

Cont. from Page 7  
several other residential centres and spent holidays in them, but this is by far the best I've seen.'

But however pleasant his surroundings Laurence, like most of the residents, enjoys the opportunity to go out occasionally and as a Catholic he likes to attend Mass regularly.

People from local churches of all denominations are very good about coming to pick us up and drive us to services.'

'Willow' area's representative was Yolande Bourton who is ambulant and one of the less severely handicapped residents. Although she has been at the centre for only three years, she found sharing a bedroom rather restricting, and is delighted to have her own bedsitter.

She appreciates the privacy in which to play her electric organ and to write poetry, some of which has been published. Like the other residents she has a personal timetable for the week pinned up in her room. These show a stimulating balance of workroom tasks, educational classes, therapy and periods of private study. Residents share these activities with five or six spastic people living in the area who come in during the day for varying periods of time.

All the residents at the Princess Marina Centre must take part in a certain amount of community activity daily. Otherwise the temptation to isolate themselves in the comfort of their own quarters might be difficult to resist.

# New President for SOS

## A starring role for Lady Anne

THE Stars Organisation for Spastics has a new President. She is Lady Anne Tennant, lady-in-waiting to Princess Margaret, and she has taken over from the Hon Mrs James Ogilvy, who has been SOS President for the past nine years.

'I was approached by Mrs Ogilvy whom I already knew — she is married to my cousin — and I felt very honoured to be asked to take on the post,' Lady Anne told **Spastics News**.

• **MEMBERS** of the Stars Organisation for Spastics meet their new President, Lady Anne Tennant (extreme left), at their March meeting. Left to right, Brian Rix, Leslie Crowther, Sylvia Syms, Dickie Henderson, Dame Vera Lynn and behind them, Jack Howarth. The giant teddy bear has been donated by a well-wisher who has asked for it to be exclusively for the use of children, and it will go to the SOS holiday hotel, Colwall Court.



### Meldreth's swinging new link with public

THE Society's Meldreth Manor School has jazzed up both its fund-raising and community involvement objectives with a scheme that is hitting all the right notes, and its success is music in the ears of deputy head Tony McEvoy.

He explained: 'A group of local people got together and decided it would be a good thing to form a jazz club and create further links with the community. We now have a committee of nine and book musicians through agents, which means that we have to raise the money at the door to pay for the concerts. Raising money is one of our goals but it is not the main objective — which is to get

people into the school to see what we are doing.'

And drawing the crowds to the school at Royston, Herts, are the top names on the British jazz scene: Kenny Ball and his Jazzmen, George Melly, Acker Bilk and his Paramount Jazz Band, Humphrey Lyttelton, Chris Barber and Terry Lightfoot.

The concerts are staged in the school's main hall and the ticket includes supper. Any-one can join the club by contacting the school's secretary and the profits from the concerts will go into a special fund to be used at the end of the year to provide extra amenities for the pupils.

### The 'loot' came home to roost

WHEN the aviary in the grounds of Wakes Hall Spastics Centre, near Colchester, Essex, was broken into in the middle of the night, everyone sadly assumed that all the birds, including a golden pheasant worth £9, had been stolen. The gardener had discovered the padlock to the aviary broken off and all the birds missing, and naturally the residents who used to help feed the birds were very upset.

However a silver pheasant and five budgerigars were later found in the grounds none the worse for their adventure, and the golden pheasant, too, turned out to be a somewhat protected species. Three days later it was found safe and sound walking across a local field, by which time eight more budgies had also come home to roost.

### After meals galore—a special lunch

FOR the best part of 14 years Elizabeth Holzinger has been the force behind the food in the kitchen at the Society's Castle Priory College, where she has been caterer/cook, but on April 2 she was on the

other side of the canteen counter at lunchtime.

For a luncheon was held to mark her retirement, attended by Derek Lancaster-Gaye, the Society's Director of Resources, and Richard Gray, Controller

of Schools and Centres.

Miss Holzinger has been at Castle Priory, apart from a short break, since 1965 and staff presented her with a clock to mark her long association with the College.

but getting to know all the residents really well. We live in London with a home in the country and it will be nice to just drop into a centre if I am passing to say "hello", said Lady Anne, who favours the informal approach as president — a direct contrast to her role as lady-in-waiting. 'Although in fact they have a lot in common. As lady-in-waiting I have to write letters and make arrangements, be very tactful and deal with the unexpected. We know three months in advance what our duties will be, so that I will be able to arrange my tasks as SOS president round that.'

#### Chatting up'

'As president I will be chatting people up, getting stars to do things for the organisation and co-ordinating. It helps that I already know lots of people. I have attended a number of SOS functions in the past, and so has my husband Colin.'

It was Colin who used to own the West Indian paradise isle of Mustique where Princess Margaret often holidays. 'When we first used to go there it was just a desert island — like something out of Robinson Crusoe — and I would take my two elder boys, Charles and Henry, out on a fishing boat to get there, when

they were about six and four.'



• LADY Anne Tennant, the Stars Organisation for Spastics' new President is welcomed by The Spastics Society's Chairman, Dorrien Belson.

Charles is now 22, Henry 20, with Christopher, 10; and identical twins May and Amy who are eight.

I didn't know I was having twins until two days before they were born, so it was a bit of a shock, although a nice one, to have daughters after three sons. The girls go to a riding school which is involved with the Riding for the Disabled Association, and I know the girls will want to come with me when I visit SOS events like the summer fete at Colwall Court.'

I am really looking forward to my term of office as the SOS president, everyone is very kind and Sheila

Rawstorne, the SOS Director, is wonderful, so I don't think I'll have any problems. I have been so impressed by what I've seen already — when I visited one residential centre a lady was doing the most exquisite knitting — one forgot that she was handicapped, she was so busy — and so happy.'

**Liz Cook**

TWO young handicapped children will have a week's holiday this summer, thanks to staff working at the Trustee Savings Bank in Lime Street, Bedford.

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# That word under fire... again!

IS THE WORD 'SPASTIC' A CRUEL AND OUTDATED LABEL, OR THE IDEAL WAY OF DESCRIBING THE CONDITION OF CEREBRAL PALSY TO THE PUBLIC? AND WORTH THOUSANDS OF SYMPATHETIC POUNDS TO THE SPASTICS SOCIETY'S FUND RAISERS? THAT WORD HAS COME UNDER FIRE AGAIN, AND WITHOUT TAKING SIDES, SPASTICS NEWS REPORTS A VARIETY OF VIEWS.

WHAT DO YOU THINK? £5 FOR THE BEST LETTER ON THIS CONTROVERSIAL SUBJECT.

# Call me a 'spastic' and you rob me of dignity, says Valerie

VALERIE Lang wants to make war on the word 'spastic.' She launched the first salvo of her attack at the Society's North West Regional Conference, where delegates heard her claim that the word was old-fashioned, inaccurate and had fallen into disrepute.

She told them: 'I am not "a spastic." I am a woman, a librarian, a Christian, a music lover and many other things besides. Or to put it another way — I am a middle-aged librarian

who happens to be mildly spastic.'

She acknowledged that in the early days of the Society it worked very well as a means of communicating to the public the reason why the Society was started. In a somewhat tart comment she said: 'I think the founding members must have chosen the name "Spastics" because it was to them short and snappy. I may add that none of them had a speech problem making "Ss" difficult.'

Because, in her opinion, the word has fallen into disrepute, she argues that there is a strong case to be

made for changing the name of the Society.

She feels that this could be done without damaging the contribution of donations and legacies since there are precedents. 'The Waifs and Strays became the much more acceptable Church of England Children's Society. Mental defectives are now known as mentally handicapped,' and she pointed out that no one these days dared to use the word "cripple" although it was once considered a perfectly respectable term.

'IF I AM NOT SEEN AS ME, IN MY OWN RIGHT, SOMEONE WHO IS FORTUNATE ENOUGH TO HAVE A JOB, SOMEWHERE

TO LIVE, A NAME, INTERESTS, LIKES AND DISLIKES, BUT AM JUST ANOTHER ONE OF THESE "SPASTICS," I HAVE NO HUMAN DIGNITY AT ALL. IT IS NOT EASY TO KEEP YOUR DIGNITY WHEN YOU HAVE TO BE FED AND TOILETED. NEITHER IS IT AT ALL EASY TO BE DIGNIFIED WHEN YOU TEND TO RESEMBLE A SAGGING MARIONETTE, NOR WHEN EVERYONE CALLS YOU BY YOUR FIRST NAME IMMEDIATELY AFTER THEY HAVE FIRST MET YOU. YET PRECISELY BECAUSE DIGNITY IS VERY DIFFICULT FOR US TO ACHIEVE, IT IS VITAL THAT THE LITTLE WE HAVE LEFT AS INDIVIDUALS SHOULD NOT BE TAKEN AWAY. IT IS TAKEN AWAY IF WE ARE THOUGHT OF AS JUST ANOTHER "SPASTIC".'



Valerie Lang

## How to turn a 'term of abuse' to advantage



Dr Firman

DR Ronald Firman, who is a member of the Society's Executive Council, said: 'I don't particularly like the word spastic, whether used as a noun or an adjective, because it is now a common term of abuse — but I am often in a position to turn it to The Spastics Society's advantage. When a student of mine calls another student "a stupid spastic" I invariably call them over and say, "he may be stupid but I am the one who is spastic." Often this leads to a discussion of the meaning of spasticity and of the work of The Spastics Society. Although I recommend this ploy I do appreciate that someone fearing ridicule from friends, work-mates and casual acquaintances will prefer not to acknowledge their spasticity.

'For my part, in my social and professional life the word spastic is irrelevant. Only within The Spastics Society and its local groups am I ever introduced as "a spastic" and made to feel aware of my spas-

ticity. Outside the charitable sphere it is my abilities as a lecturer, consultant geologist, etc., and not my disabilities which are important. In fact as long as I function within my capabilities (and everyone has physical and mental limitations) the question of disability never arises and if it does the all embracing term "spastic" is not very helpful.'

I am very interested in the etymology and changing use of the word. In my own science of geology we have palinspastic maps which are nothing to do with spastics moving backwards (palin from the Greek meaning back or moving backwards). "Spastic" is used in a very restricted and specialised sense by the medical profession and in other sciences. In human terms the important point is that it is now commonly used, both as a noun and an adjective (see the current paperback Oxford Dictionary) to describe a person suffering from cerebral palsy and has become, through its easy alliteration with the word "stupid," a convenient abusive term applicable to anyone or anything which is slow and clumsy.

Since many who were born spastic now find this latter usage so intolerable that they refuse to admit to being spastic, I feel we should avoid the word wherever possible, never using it in reference to an individual without his or her express permission.

## 'Rubbish' to argue over a word

JANET Swanton is a telephonist with a firm of estate agents, and has been chairman of the Southend Spastics Group for the past three years. She said: 'The word has never worried me at all. I have never minded it — after all you've got to be called something. I am very lightly handicapped, but those I know who are more severely disabled have never minded.

'The arguments against the use of the word "spastic" are rubbish because everyone is labelled in some way — Mr and Mrs Average or "normal person." Those can be just as offensive terms and anyway — What is normal? A friend of mine said: "You don't pat a bald-headed man on the head and give him a sweet just because he is bald. The only thing I ever thought odd was when spasticity was thought to be contagious."

'To me this is a very old argument. I don't mind the word "spastic" because that is what I am, and it is only a word after all — it does not alter you as a person.'

## 'Disabled or handicapped' — but never 'cripple'

RESIDENTS at The Spastics Society's Coombe Farm Centre in Surrey told Spastics News what they felt about the word "spastic" — and how they liked to be described.



KIM Jessup is 30 and adamant: 'I don't like the word "spastic." I prefer "disabled." The word "spastic" hampers me before I even go out because people are apprehensive of the term whereas they are not nearly so worried about someone being handicapped.'



STEPHEN Harding is 26. He says: 'I just like to be called "disabled" — rather than "spastic." Obviously we have got to be labelled something but as far as the general public are concerned they might just as well call us "handicapped" and medical people will always call us "cerebral palsied".'



ANNE Hall said: 'I have been at Coombe Farm for 23 years and I had not really thought about what other people called us. I do not like the word "spastic" but I think it is better than saying "disabled" because it is more specific. It shows people know what they are talking about.'



MARGARET Fensome said: 'I do not like the word "spastic" because I do not think it sounds very nice but a word like "cripple" offends me more. "Handicapped" I can take but "cripple" — ugh! The first time I ever heard the word "spastic" was 23 years ago when I went to hospital. I had been to an ordinary school and I never had any trouble, they all treated me as one of them. I am only lightly disabled and my condition only shows when I am very tired.'



ALICE Maddock's answer was brief and to the point: 'I prefer to be looked on as a person. I am an individual.'

## 'The Society would lose millions'

MICHAEL Brophy, the Society's Director of Fund Raising said: 'Valerie Lang may well be right — this is a problem which has been taxing the Society for a number of years and we have always decided so far, to play it safe by not changing the name. If we changed the name the Society would lose millions of pounds overnight because the sympathy evoked for sufferers of cerebral palsy is not the same as that evoked by sufferers of spasticity. Furthermore the semi-automatic donations from millions would cease.'

'On the negative side — it would cost in excess of £100,000 to physically change the name of the Society where the Pools, stationery, direct mailing, etc., and all the other publicity is concerned. I also think that there is not much point in euphemisms and what we have to do is make the public regard spasticity in the same way that Miss Lang knows certain people regard cerebral palsy and that the association in their minds should be the same.'

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